

USING THE VOICE OF THE PATIENT TO IMPROVE CARE IN CHICAGO AND BEYOND









Project Patient Care Newsletter - December 2019

Project Patient Care wishes you, your family, and friends a wonderful holiday season and a healthy and joyous New Year!

As we close out the year, we want to reminder everyone of the importance of getting your flu and pneumonia vaccines and staying current with your immunizations. (Refer to Centers for Disease Control and Infection info by clicking Here)

If you have not had your seasonal flu vaccine, please consider getting your flu vaccine today. If you are 65 years and older; smoke cigarettes and are between the ages of 19 and 64 years old; or have specific compromised medical conditions - please get your pneumonia vaccine PPSV23 if you have not already. The pneumonia vaccine, PCV13, is no longer suggested to be given unless you meet certain clinical conditions or your clinician advises you to get the vaccine.

By giving yourself the gift of the seasonal flu vaccine, you are also giving others a gift by helping to stop the spread of flu to other family members and friends that may not have been immunized.

For this 2019-2020 flu season, as of December 13, 2019, the CDC reports that 1,300 people have died from the flu so far this season and there have been an estimated 2.6 million flu illnesses and 23,000 flu-related hospitalizations. Each year in the United States, about 1 million people have to seek care in a hospital due to pneumonia. Most of the people affected by pneumonia in the United States are adults.

If you are not convinced about keeping current with season flu vaccines or pending your age or medical condition, the pneumonia vaccine, read on.......

The flu can become pneumonia. In fact, about one-third of all pneumonia cases in this country are caused by respiratory viruses, most commonly influenza. According to the American Thoracic Society, Pneumonia is the most common cause of sepsis and septic shock, causing 50% of all episodes of sepsis and septic shock. While all patients that develop sepsis or septic shock are not

from flu or pneumonia, all sepsis cases do start with an infection.

Our December 2019 Champion Change Agents are Sarah Kiehl and Armando Nahum who share their experiences with sepsis and why it is so important to act quickly if you suspect sepsis. We also hope that you will understand the linkage between infections and sepsis - and will take preventive approaches to reducing your risk in getting sepsis by being properly immunized.

PPC's goal of the Champion Change Agents Podcast series is to bring the voice of the patient, family, and caregiver to the forefront on important health and healthcare issues and to advance policy discussions on quality, safety, and cost of care.

In this newsletter, you will find information on:

- December Champion Change Agents
- Sepsis Keep Raising the Awareness
- Caregiver Input Administration for Community Living
- New QIN-QIO Contracts and State Coverage
- Academy for Health Scholarships for Patients and Patient Advocacy Groups
- MANY Technical Expert Panels Patients Needed

CHAMPION CHANGE AGENTS

December 2019



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Champion Change Agents
December 2019

Our December 2019 Champion Change Agents are Sarah Kiehl and Armando Nahum. Sarah fought a ferocious battle with sepsis shortly following a procedure after the birth of her twins. Armando's son, Josh, developed sepsis following a procedure and unfortunately was not able to win the sepsis battle and died at the age of 27.

PPC's December Podcasts (available by Dec. 24) are focused on the impact of sepsis; signs and symptoms of sepsis; and the importance of acting fast if you or a loved one suspect they have sepsis. To listen to Podcasts, click here

SEPSIS

Sepsis is the body's overwhelming and life-threatening response to an infection which can lead to tissue damage, organ failure, and death. Sepsis is the cause of death for approximately 270,000 Americans each year according to the Sepsis Alliance.

According to a report of the Health Research and Education Trust (HRET) of the American Hospital Association, Sepsis is diagnosed in over one million patients each year in the United States. "In 2011, sepsis treatment resulted in an estimated \$20.3 billion in health care costs, 5.2 percent of the total cost for all hospitalizations, and was the most expensive condition treated. Sepsis is not only expensive and prevalent; patients diagnosed with sepsis are estimated to have a mortality rate of 28 percent to 50 percent."

If you suspect sepsis, call 911 or go to a hospital emergency room as the hospital staff will be in the best

ACTING QUICKLY CAN SAVE LIVES FROM sis is your body's life-threatening respon an infection and is a medical emergency When it comes to sepsis, remember IT'S ABOUT TIME™. Watch for: **TEMPERATURE** higher or lower than normal INFECTION may have signs or symptoms of infection **MENTAL DECLINE** confused, sleepy, difficult to rouse **EXTREMELY ILL** "I feel like I might die," severe pain or discomfort CALL 911 OR GO TO A HOSPITAL AND SAY Take the **TIME** to learn the signs at sepsis.org. SEPSIS ALLIANCE position to rapdily assist you. Let the emergency room staff know that you suspect sepsis.

CAREGIVER INPUT NEEDED Administration for Community Living

Our November 2019 Newsletter featured articles on the important and growing role of caregivers. We had several inquiries about the Administration for Community Living (ACL) - its role and how they could get involved.

The ACL was established in 2012 by the U.S. Department of Health and Human Services. According to the ACL, "ACL brings together the efforts and achievements of the Administration on Aging (AoA), the Administration on Intellectual and Developmental Disabilities (AIDD), and the HHS Office on Disability to serve as the Federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older Americans and people with disabilities across the lifespan."

In 2018, Congress passed two pieces of legislation aimed at caregiver support: The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act will establish a Family Caregiving Strategy to better support families; and the Supporting Grandparents Raising Grandchildren Act focuses national attention on better understanding the complex needs of grandparents and older relative caregivers.

The RAISE Family Caregivers Advisory Council (FCAC) met for the first time in late August 2019 with a charge of creating strategic pathways and resources for caregivers. The RAISE FCAC is supported by a unique group of collaborators - The John A. Hartford Foundation, the National Academy for State Health Policy (NASHP), and ACL. The RAISE FCAC is seeking individual and organizational caregiver input on pressing issues caregivers are facing and recommendations on how best to address the pressing issues. You may provide input through February 7, 2020 by clicking **Here.**

The Grandparents Raising Grandchildren Advisory Council (GRGAC) also met in late August 2019 with a goal of identifying resources available and gaps in resources for grandparents or older relatives taking care of children. The gaps focused on health, education, nutrition, social services, and legal services. The GRGAC is also soliciting input on resources, including:

- Best practices, resources, and other useful information for grandparents and other older relatives raising children
- Gaps in available resources
- Unique needs of children affected by opioid misuse
- Unique needs of members of Native American tribes.

To submit your input to the GRGAC, click Here.

NEW QIN-QIO CONTRACTS AND STATE COVERAGE

In November 2019, the Centers for Medicare and Medicaid Services (CMS) announced the five-year contract awards for the Quality Innovation Network - Quality Improvement Organizatins (QIN-QIOs). 11 organizations were awarded contracts with several of the organizations having various sub-contractors that will aid in providing the quality improvement support in each state, Puerto Rico, U.S. Virgin Islands, and U.S. Pacific Territories. The QIN-QIOs will work collaboratively with providers on patient safety, quality improvement initiatives, prevention and management of chronic disease conditions, opioid treatment and alternative therapeutic treatments, and community based health and healthcare initiatives. QIN-QIOs will also be seeking local community patients, families, and caregivers for advisory councils and to join theBFCC initiatives. To contact your state QIN-QIO, please click Here.

Earlier this year, CMS announced that Livanta and KEPRO were awarded the contracts for the Beneficiary and Family Centered Care Quality Improvement Organization (BFCC-QIO). Any Medicare beneficiary or their representative who have a complaint or quality of care concern can get help from their BFCC-QIO. BFCC-QIOs manage all complaints and quality of care reviews, EMTALA and other types of case review for people with Medicare and their representatives. To contact your state BFCC-QIO, click Here.

Academy for Health Scholarships for Patients and Patient Advocacy Groups - Deadline TODAY

CMS Technical Expert Panels In Need of Patients Deadlines Approaching

PPC often hears about opportunities for patients, families, and caregivers to get involved in research, measurement development, or sharing their story. We would like to make you aware of these opportunities as they become available.

Academy for Health Scholarships. The Academy of Health in support of patient participation at the Health Datapalooza AND the National Health Policy Conference, has made available a limited number of complimentary registrations and full patient scholarships. **Deadline is today** - to apply click **Here**

CMS Technical Expert Panel. CMS has several Technical Expert Panels (TEPs) they are recruiting for and are interested in having patient, family, or caregiver participants on the TEPs. Please note these TEPs have specific patient, family, caregiver needs.

The TEPs and the self-nomination deadlines are listed below:

- Development and Reevaluation of Total Hip and Knee Arthroplasty Outcome Measures -Deadline January 31, 2020
- Home and Community Based Services (HCBS) Measure Development, Endorsement, Maintenance, and Alignment Contract—Medicaid and Children's Health Insurance Program (CHIP) Scorecard Measures Gap Development - Deadline January 16, 2020
- Home and Community Based Services (HCBS) Measure Development, Endorsement, Maintenance, and Alignment Contract—HCBS Measures January 16, 2020
- Development of a Quality Measure Assessing Delay in Progression of Chronic Kidney Disease (CKD) January 13, 2020
- Development of Functional Outcome Quality Measures for Home Health Agencies (HHAs) January 17, 2020
- Development of Days at Home Quality Measure January 9, 2020
- Maternal Morbidity electronic clinical quality measure (eCQM) Deadline December 20, 2019 Seeking patient with maternal morbidity

To find out more about the CMS TEPs and how to apply to be a patient representative, Click Here

We Love to Hear From You!

We are always happy to hear from you - please feel free to contact us at any time.



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Thank you